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## Included in Training and Work

Waltz, M.M.

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# REPORT

## INCLUDED IN TRAINING AND WORK: *Transforming policies and practices for people with disabilities*



**DISABILITY STUDIES**

in Nederland



**Source:** Educational materials collection, Disability Studies in Nederland. This collection has been developed to share Disability Studies concepts, research and information with students and educators.

### Interpretations, associations and meanings associated with the olive tree:

*The olive tree is known for its characteristic form and delicious fruits, its attractively coloured leaves, its slow growth and longevity, and the fact that, unlike many other trees, it retains its leaves in the winter. It is not difficult to care for or to value, but one must invest in proper care so that the tree can thrive.*

*We use the olive tree as a symbol of the theme "Training, work and inclusion," because this theme focuses on the possibilities and talents inherent in all people. If we value living and working with people with disabilities, the saying "diversity means wealth" becomes more than just a slogan. When we discover and develop the talents of disabled people in the right context, we are all the richer for it.*

**A note about language:** For many years, we have been encouraged to use people-first language, e.g., 'person with schizophrenia.' In recent years, some people with disabilities (especially those with autism in the US and UK) have challenged this usage, noting that it implies that their difference is something undesirable that is separate from themselves. For this reason we have used both people-first and impairment-first language in this report.

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The cover image is based on a photo from Cassie McLellend of WheelieAwesome Costumes (<https://www.etsy.com/nl/people/cassiemclelland>).

## INTRODUCTION

In 2017, Disability Studies in Nederland launched a research process that culminated in a one-week NIAS-sponsored scientific workshop at the Lorentz Centre, University of Leiden. Experts with and without disabilities worked together to research, discuss and make evidence-based recommendations through pre-workshop working groups and during the intensive workshop process itself.

Our end goal was to create **an evidence-based vision of what truly inclusive, talent-driven, effective vocational education would look like** for adults with disabilities. This vision includes attention to the intersectional nature of the barriers faced by disabled people—the ways that disability intersects with race, ethnicity, gender, social class and normativity to produce the poor outcomes we all too often see today. Our participants contributed based on their knowledge of the best current research, and through their contributions we learned where the research base for current practices is strong, and developed a clear roadmap for necessary additional research.

This report summarises the results of this process.

The work process was illuminating, and sometimes exhausting. In the months leading up to the Lorentz Centre workshop, four workgroups were formed to focus on barriers to and facilitators of inclusion in training and work that had been identified in previous research. These workgroups kicked off the intensive workshop process by presenting their findings. During the rest of the week there were formal presentations, solution-focused small-group meetings on additional barriers and potential solutions, and late-night discussions, culminating in an outline that we could all agree on taking forward.

The Lorentz Centre workshop participants are truly co-authors of this report: their research skills and hard work made it possible. We would also like to thank Yuki Tol and Obbe Willebrands of Gemeente Amsterdam, Sarah Willems from Konekt/LetsCo, Henriëtte Sandvoort of LFB Nederland, Prof. Katherine Runswick-Cole of Manchester Metropolitan University, Maurice Vermunt of LDC and WerkConsult, members and directors of the inclusive dance company Platform-K, Ronald Ligtenberg of Possibilize, and Drs. Teun Post of ROC Landstede. For their facilities and generous support, we thank the Netherlands Institute for the Advanced Study in the Humanities and Social Sciences (NIAS), and especially Tara Seeger and the Lorentz Centre team; and also Gemeente Leiden, which supported the fantastic performance/workshop of Platform-K.

Since the end of the workshop, I have worked under the auspices of Disability Studies in Nederland to bring the document you now hold into being by expanding on the outline. I hope you will find within it provocative ideas for transforming policies and practice—it isn't always clear what we must do in every given context, but as the existing model is not keeping pace with rapid change in education and work, it's time for a change.

Regards,  
Dr Mitzi Waltz  
Senior Researcher, Disability Studies in Nederland  
Docent in Public Health, Athena Institute, Vrije Universiteit Amsterdam

## COLOFON

**Editor:** Dr. Mitzi Waltz

**Co-authors (in alphabetical order, Netherlands except as noted):**

- Amit Koikkara Ajit, Delft University of Technology (India / Netherlands)
- Dr. Alma Akkerman, Cosis Expertisecentrum
- Dr. Minne Bakker, Vrije Universiteit Amsterdam
- Lujan Blankenstein, UWV / Personen uit het Autistische Spectrum (PAS)
- Drs. Karin van den Bosch, freelance webeditor and project member, Karins Consultancy / Disability Studies in Nederland
- Maaïke Callens, Steunpunt Inclusief Onderwijs (SIHO) (Belgium)
- Dr Tsitsi Chataika, Lecturer, University of Zimbabwe; Research Fellow, Manchester Metropolitan University (Zimbabwe / UK)
- Prof. Dr. Claudia Claes, Docent/decaan, Faculty of Education, Health and Social Work, University College Ghent; Visiting professor, Ghent University (Belgium)
- Dr. Ikenna Ebuenyi, Researcher and PhD Candidate, Vrije Universiteit Amsterdam (Nigeria / Netherlands)
- Miriam Hemelsoet, educationalist, KONEKT (Belgium)
- Drs. Andries Hiskes, University of Leiden / The Hague University of Applied Sciences
- Prof. Geert van Hove, Vrije Universiteit Amsterdam/Gent University (Belgium)
- Selma van Huijzen, MSc, Hogeschool van Rotterdam
- Jolanda Huizer, ZonMW
- Judith Jansen, Handicap + Studie Expertisecentrum, 's Hertogenbosch
- Margriet van Kampenhout, Argenta Consult
- Steven Kapp, University of Exeter (US / UK)
- Drs. Jacqueline Kool, Disability Studies in Nederland
- Valesca Lindenberg, Heinrich-Heine-Universität Düsseldorf (Germany / Netherlands)
- Dr Nicola Martin, London South Bank University (UK)
- Linda Nieuwenhuizen, UDL Nederland
- Drs. Hanna Peels, Middin
- Dr. Alice Schippers, Disability Studies in Nederland/ Vrije Universiteit Amsterdam/International Association for the Scientific Study of Intellectual and Developmental Disabilities
- Drs. Sofie Sergeant, Vrije Universiteit Amsterdam/Disability Studies in Nederland
- Irma van Slooten, UDL Nederland
- Elena Syurina, Vrije Universiteit Amsterdam
- Dr. Edwin Luitzen de Vos, consultant/researcher on inclusion of young people with disabilities
- Dr. Mitzi Waltz, Disability Studies in Nederland/Vrije Universiteit Amsterdam (US / UK / Netherlands)
- Diederik Weve, Shell/Personen uit het Autisme Spectrum (PAS)
- Evelien Westerbeek van Eerten, Handicap + Studie Expertisecentrum

## THE SCIENTIFIC CASE FOR CHANGE

### The problem.

People with disabilities experience disadvantage and discrimination in the job market, and are often unemployed. This impacts their lives financially and may have additional impacts in terms of self-esteem, social inclusion, and subjective feelings of belonging.

Worldwide, people with disabilities are by far the largest “minority group”: about 15 percent of the population (World Health Organisation, 2011). However, they have a far lower rate of employment than non-disabled people. In Western Europe, about half of people with a disability are in employment (Remploy, 2014); in low and middle income countries, only about 20 percent are employed (Heymann, Stein, & Moreno, 2014). For people with intellectual disabilities or mental health conditions, the rate is far lower in all countries (*ibid.*)

Adult vocational (special or inclusive) education and specialist support exist to remedy this situation, but we know that these are not as accessible or effective as they could be. All too often, adults with disabilities, and especially those with intellectual or developmental disabilities or significant physical disabilities, find that they cannot access vocational education, or that they have not had adequate preparation in vocational education for real-world work. Outcomes of vocational education are significantly less positive for people with disabilities (Cavallero, *et al.*, 2005).

### The causes.

Some of the reasons for this disparity are known. For example, segregation within the primary and secondary education system has a direct impact on access to vocational education and work, as illustrated in the case of Germany by Waldschmidt and Weinert (2010). People with disabilities may experience continuing psycho-social effects of exclusion and bullying that occurred during schooling, and may continue to encounter these exclusionary practices within vocational education, work, housing and community life (Pfahl, 2004; Fevre, *et al.*, 2013; Durbin-Westby, Ne’eman and Topper, *et al.*, 2012; Paludi, 2015).

Other reasons are contested or not well researched, but are likely to include the design of educational facilities and materials (Meyer, Rose and Gordon, 2016), and (mis)alignment of vocational education content with employer needs.

Without developing evidence about the source of inequalities, it is hard to develop adequate policy and practice responses (Claes, *et al.*, 2015). Indeed, systematic data for monitoring and evaluating effective technical and vocational education and training programmes are lacking (UNESCO, 2015).



It is not possible to consider perceived failings of vocational training without also considering the role of employers in hiring those trained. They may be unwilling, unable, or uncertain of how to employ disabled people within a competitive workplace, regardless of how well-prepared and well-educated they may be (Winn and Hay, 2009; Martin, 2009; Coleman *et al.*, 2013). If this is a primary barrier, changes to vocational education alone will not produce results. Disabled Peoples Organisations (DPOs), Non-Governmental Organisations (NGOs) and academics worldwide have highlighted how direct and indirect discrimination by employers can block access even for well-prepared applicants (for example, Heymann, Stein and Moreno, *op cit.*; International Labour Organisation, 2015).

## **The individual and societal impact.**

Both individual quality of life and society at large are impacted. People with disabilities often end up reliant on disability benefits, sometimes because a viable alternative isn't available, and experience constrained life chances and a poor quality of life as a result. They may be penalised or sanctioned for being workless. Talents are left undeveloped, and potential contributions are lost (Bruyère, Golden and Karur, *et al.*, 2012). The international Labour Organisation estimates the cost of this wasted potential as a loss of between 3 and 7 percent of potential world GDP (International Labour Organisation, *op cit.*)—but given the number of disabled people worldwide, this estimate may well be very low.

In addition, a parallel world of disability-specific vocational education and work has emerged where disabled people attend endless rounds of vocational education courses and temporary trainee placements that can be costly in financial terms but still do not lead to viable employment. As the European Association of Service Providers for Persons with Disabilities has noted, “People with disabilities are often unable to complete official Vocational Education and Training (VET) programmes, and are often restricted to participating in tailor-made VET courses, which unfortunately do not grant the student any official certification of their gained qualification” (EASPD, 2015).

Others work in businesses, “social enterprises” or sheltered workshops for no or low pay, often in the guise of vocational training or experience. In this world, most managers, trainers, employers and decision-makers are non-disabled people. People with disabilities may have no choice about whether to participate in this system, as agreeing is often a criteria for receiving benefits. Incentives can arise that ensure that disabled people remain outside the world of mainstream work, even when their labour is enhancing the balance sheets of major companies. In Australia, the UK and the US, for example, many major employers now rely on free labour provided through “welfare-to-work” programmes, much of it performed by disabled people. Employers are incentivised to take on, and then discard, disabled workers. Some research has found that participants in these programmes are actually *less* likely to obtain paid, sustainable employment than other benefit claimants who are not forced to take work placements (e.g. Hale, 2014).

It is striking that in Europe, employment rates for disabled people have actually fallen in recent years, and the EU now ranks “below average” in this area (Fembek *et al.*, 2014: p.

11). Very little high-quality research exists that explores the experiences of disabled people in this system, or alternative routes that result in sustainable paid employment.

In the worst-case scenario, there is the “school-to-prison pipeline,” which disproportionately affects young people with disabilities and particularly those from racial or ethnic minorities, and which has catastrophic personal and social costs (National Council on Disability, 2015). While well-known in the US, effective responses to the “school-to-prison pipeline” have not been developed via research. This phenomenon is likely also present in Europe, Asia and the global South, but documentation is poor. Whenever researchers have looked—for example, in the Edinburgh Study of Youth Transitions and Crime (McAra and McVie, 2010)—evidence has been clearly documented time and time again. This linkage represents high costs to both individuals and society.

## STRUCTURE OF FINDINGS AND RECOMMENDATIONS

We began before the workshop by compiling an evidence base in four key areas:

- Matching individual skills and talents to appropriate VE and work opportunities by working collaboratively with disabled people
- Applying Universal Design for Learning (UDL) principles to vocational education and work placement
- Dealing with the issue of bullying in the context of vocational education
- Work, “participation,” inclusion and preventing discrimination

This work was followed by further research during the workshop on the following areas, which were identified as additional priorities during the research process:

- Stigma, disclosure and reasonable accommodations
- Supporting freelancers and flexworkers with disabilities
- Stress in training and work
- Mentoring and supportive feedback
- Belonging—Integration of people with disabilities into school or work groups

The following section is comprised of one-page summaries covering findings and recommendations in each of these areas. Each follows the same simple structure of identifying Aims, Barriers, Facilitating factors, and Recommendations.

These summaries followed by a conclusion that restates our key recommendations, and a *References* section.

There will be recognition that “one size fits all” solutions are not possible, and that attempts to impose these through institutional, local and national policies is one reason for some of the difficulties observed. Vocational education needs differ for individuals, specific groups of disabled people, specific industries, and economic conditions.

We also recognise that the flow of knowledge and expertise has often been limited based on geopolitical power structures, often to the detriment of disabled people. Policies and practices that are appropriate in a small Dutch village in a wealthy province, where most work involves formal agreements between employees and employers, may not translate well or at all to conditions in a poor urban area on the outskirts of Lagos, Nigeria, where most work involves either self-employment or casual labour without formal employment agreements. However, the increasing casualisation of labour in developed countries means that there may be much to learn from successful strategies employed in the developing world.

## Matching individual skills and talents to appropriate (vocational) education and work opportunities by working collaboratively with disabled people

It is crucial to determine an individual's interests, abilities and aptitudes and skills to identify vocational strengths, needs and career/human potential. This is true for people with and without disabilities. This can't be done with standardised assessments, such as interest checklists or examining a file. It is crucial to open up spaces for discussion and collaboration, especially when working with disabled people whose past experiences of education or work may not have been very successful.

### Aims

- Actively and creatively identifying talents
- Finding contexts in which those talents can flourish
- Ensuring that people with disabilities are seen as people who can contribute (Villa, Thousand and Nevin, 2000)
- Developing and benefiting from the abilities and talents of disabled people
- Achieving workplace diversity
- Promoting belonging for all in training and the workplace

### Barriers

- Expectations of people with disabilities and of assessors
- Under- and over-estimation of capabilities
- Need to accomplish skill mastery
- Self-disclosure
- Stigma (*see p. 19*)
- (Dis)ableism
- Fast pace and pressure to perform, with potential results that include injury or worsening of disability, stress (*see p. 22*)
- Bullying (*see p. 15*)
- Lack of inclusive education in past, or difficulty finding inclusive training now

In addition, we found that tensions can arise when staff supporting choice-making are not trained to communicate in a way that presumes competence and gives respect to clients, especially when working with non-verbal people, or when support staff are also responsible for workplace safety and/or meeting production targets. Questions have also been raised about the availability of good tools for assessing the competencies and interests of people with intellectual and/or psychiatric disabilities. Assessors are unsure whether the instruments being used are of high quality, accurate, and applicable for individuals with varying degrees of impairment.

### Facilitating factors

- Presuming competence
- Active support rather than supportive policies or arms-length help

- Inclusive education
- Celebrating diversity in the workplace
- Adjustments to recruiting policies, work information, and work practices
- Collaborative and participatory policymaking (Beresford, 2016)

## Recommendations

Researchers have found that *active support* is often needed to provide and facilitate choice (Beadle-Brown, Hutchinson and Whelton, 2012), especially for people with intellectual or developmental disabilities. However, by supporting disabled people adequately to make informed choices, we facilitate self-determination and the formation of strong identities as learners and workers. Examples of creative ways to support choice include using drawings and photos, for example, the Drawing Lab process (van Hove, 2016) and use of the EBB app, which incorporates Photovoice and Photo-elicitation (Sergeant and Verrejt in: Schippers, 2010).

The conditions for supporting choice include an accepting and non-controlling environment: choices must be truly based on individual interests and aptitudes, not “what’s available in our programme,” “what we’ve always done,” or “what people with [disability x] are supposed to be good at.” Choices offered need to satisfy the person’s need for autonomy, competence, and relatedness, as indicated by self-determination theory (Deci and Ryan, 2000). How and when support is provided must depend on the individual’s needs, but there is a common factor: *respect* for making choices.

We found positive examples related to the *Participatiewet* (Participation Law) in the Netherlands, which some creative support professionals have used to find satisfying and useful training and occupations for clients. We also saw and heard evidence of positive practices in Belgium (for example, the skill-matching and support work provided by Let’sCo), including a performance by inclusive dance company Platform-K during the workshop.

However, we did not find many national policies that included supported choice-making and skill-matching as part of helping people with disabilities find work. Part of the problem may be that it can be hard for professionals to see people who need support (especially people who need support for activities of daily living as well as in education and work) as having the capacity to make independent choices. We note that the concept of absolute independence is fictional for non-disabled people as well—all trainees and job-seekers rely on advice and help from families, friends, fellow trainees, teachers, co-workers and supervisors. Moving towards seeing these everyday forms of support and individualised support as existing on a continuum could help to address some of the barriers identified.

## Applying Universal Design (UD) and Universal Design for Learning (UDL) principles to vocational education and work placement

The basic concept of Universal Design is simple: Designing products and environments to be usable by all people, to the greatest extent possible. Extending this concept to learning materials and processes (Universal Design for Learning) and the workplace simply makes sense—it isn't enough to stand up for the rights of people with disabilities to join programmes that are a poor fit, we need to make opportunities that suit everyone. UD/UDL reduces the need for specialised adaptations and supports for people with disabilities. Often the UD/UDL process also reveals and overcomes hidden barriers to achievement and productivity that affect other learners and workers as well.

### Aims

- To make learning and work environments usable for everyone.
- To minimise costs associated with specialist accommodations and support.
- To create space for people where they can belong and contribute.

### Barriers

- UD principles are not yet incorporated into building codes.
- UDL principles are still new to most education systems.
- Vested interests may find change to spaces and processes difficult.
- Sometimes current policies or rules disincentivise UD/UDL.

### Facilitating factors

- UD is enshrined within the UN CRPD.
- In the World Report on Disabilities (2011), the World Health Organisation states that UD is a key strategy for reducing functional disability.
- Many countries are now placing inclusive education as a right for learners, or reforming segregated systems to facilitate inclusion.

### Recommendations

We identified three prerequisites for UD/UDL:

- Creation of a “culture of accessibility”
- Effective enforcement of laws and regulations
- Better information on environments and their accessibility

Institutions, whether these are educational institutions or workplaces, can be slow to change—but we can use legislation and policy to ensure that new spaces and programmes follow UD/UDL principles. This is about both *physical spaces* and how *learning and work materials and tasks* are designed.

We can also look to ways of providing education outside of institutions (“special” or otherwise), and ways of increasing the flexibility of education at all levels. Examples here

include sweeping away entry qualifications (age limits, requirements for specific diplomas or courses, etc.) and programme restrictions that act as barriers for not only people with disabilities, but also people with caring responsibilities, people from socioeconomically deprived backgrounds, and those whose early experience of education was unsuccessful. Modular programmes at secondary, college, vocational training, and university level will allow trainees to pursue education focused on a personal learning need, or to complete programmes at their own pace. Judith Jansen of Handicap + Studie Expertisecentrum presented information about how this could be done in Dutch higher education, and examples from other countries, such as the US and UK, were also presented.

Attention is also needed to ways in which education finance rules may limit access, especially for people with disabilities who are over age 18.

We recognise that some individualised accommodations will always be needed, but UD/UDL should work to make these the exception rather than the rule. Tailored support for learners is additional service that may be needed, especially before UDL has become the norm in education. There is quite a bit of excellent research available in the area of supported education (for example, Korevaar, 2015; Hofstra and Korevaar, 2016; Korevaar, Hofstra and Bassant, 2016), but current practices are not always evidence-based.

## Bullying in the context of education and work

The UK Equality and Human Rights Commission (Coleman and Sykes, 2016) states that “bullying” is too soft of a word for what many disabled people endure at school, in training and at work: they suggest that calling it identity-based harassment, and in some cases abuse, is more accurate. The statistics are clear in the few countries that have investigated: four-fifths of disabled people are bullied at school, and people with disabilities are twice as likely to report harassment at work. Disabled women are *four times* as likely to report harassment at work. However, most harassment and abuse goes unreported (Feldblum and Lipnic, 2016). Bullying, harassment and abuse of disabled people, and the way it is ignored and excused, are aspects of what Goodley and Runswick-Cole (2011) have called the “violence of disablism.”

In addition, research indicates that workplace harassment of disabled people, and especially disabled women, is far more prevalent in manual and low-level administrative work (Dick-Mosher, 2015). Women were also more likely to be refused accommodations (*ibid.*) The impact on people with disabilities cannot be ignored. It leads to people leaving education or work, mental ill health, and long-lasting disengagement from mainstream society. There is also an impact on disabled people who are not bullied—it discourages self-disclosure or asking for reasonable adjustments, leads to low self-esteem, and encourages stigma.

### Aims

- To ensure that all learners, trainees and workers are free from harassment and abuse.

### Barriers

- Stigmatisation of disability (some impairments are more stigmatised than others)
- Placement of disabled people in socially devalued education and work settings
- Lack of powerful, protective allies (sometimes due to fear of stigma by association)
- Setting/workplace factors: “poor information flow, an authoritative way of settling differences of opinion, lack of mutual conversations about the tasks and goals of the work unit, and insufficient possibilities to influence matters concerning oneself” (Vaarta, 1996)
- Sometimes, teachers or supervisors are involved in bullying themselves – they may use it to control student/worker behaviour.
- Some adult education settings and workplaces do not take bullying seriously. Lack of response is seen as giving permission.
- Social factors: “In the age of social media ‘adult bullying’ for want of a better term is on the rise. I think people are finding it more acceptable to harass and insult each other across all sorts of mediums.” – Jenni Richardson, MIND (2013)
- Adult learners and workers fear using internal reporting systems or legal remedies. They fear losing their training place or job, retaliation.
- Internal reporting systems and legal remedies can be inaccessible (physically inaccessible facilities for tribunals; difficult forms; high costs; lack of support).



## **Facilitating factors**

- Strong national policies that include legal remedies
- Strong internal policies in training facilities and employers, backed by robust reporting systems, penalties, and support for affected individuals
- Reduction of disability-related stigma
- Training for teaching and supervisors about recognising and addressing bullying

## **Recommendations**

### **Societal level:**

- Stigma reduction campaigns
- Governments: Legal protection, advice and support for best practices and improvements. Sweden's 1993 code is a strong model for a national anti-bullying policy for the workplace.
- General or model codes of conduct, best practices documents (e.g. from unions, employer federations)

### **Education facility/workplace level:**

- General safety measures (eliminate “danger spots” for bullying)
- Clear codes of conduct
- Improve reporting systems – encourage reporting
- Be observant
- Act on reports / observations
- Skill-building for teachers, supervisors, co-workers with and without disabilities
- Mentoring

## **Research base notes**

We found that research into bullying of adults in training and work is lacking and of poor quality, despite the prominence of bullying in individual and NGO accounts of training and work problems and failures (for example, Cocks and Thoresen, 2013).

Anti-bullying programmes are widely used in schools, but few have been evaluated for efficacy, and those that have been evaluated have often been found to have limited value. Therefore it is not certain that these could be adapted for use with adults. Training for managers is sometimes available (e.g. from ACAS in the UK) but efficacy has not been investigated. No evidence was available on effective support for victims of disability-related bullying. There is frequent recourse to a rhetoric of “building resilience” in people with disabilities, but this often looks and feels like victim-blaming. Why should disabled people be forced to put up with harassment and abuse?

Attention is needed at all levels of this issue: governmental, societal, training/work sector, specific education/work settings, individual (support, prevention and remedies).

## Work, “participation,” inclusion and preventing discrimination

There is clear evidence that facilitating disabled peoples’ participation in society through education, volunteering and paid employment is an important way to encourage inclusion (for example, van Niekerk, 2009).

Of course, for proactive measures to work, we must also prevent direct and indirect discrimination.

### Aims

- To ensure that all people can participate in society, including in paid employment, regardless of disability status.
- To ensure that people with disabilities are included in training and work on an equal basis.

### Barriers

- Direct and indirect discrimination against people with disabilities.
- Unintentional barriers to participation and inclusion, such as accessibility issues.
- Difficulty mustering the creativity, flexibility and support required to fully include disabled people.
- Under- or over-estimation of abilities, which can lead to segregation of disabled people in inferior training, permanent voluntary work and/or low-wage employment.
- Existing systems of segregated training and employment may be resistant, or may be incentivised by existing funding streams, policies and practices.

### Facilitating factors

- Commitment on the behalf of training programmes and employers.
- Policy frameworks and guidelines that prescribe participation and inclusion, for training providers, employers, unions and employers organisations.
- Strong, enforced laws about disability discrimination and intersectional forms of discrimination.
- Inspiring examples of how training programmes and employers can improve participation, inclusion, and access to paid work—and especially *sustainable work at and above the living wage*.

### Recommendations

In the EU, there has been a move from “work first” to “train first” approaches regarding disabled people and unemployment. This shift recognises the impact of the economic crisis and changes in the labour market (such as robotisation, decreasing demand for low-skill workers, and labour mobility) on these workers (Organisation for Economic Co-operation and Development, 2010). However, people with mental health difficulties and intellectual disabilities are benefiting least from positive changes—targeted, individualised approaches

are needed (Beyer and Beyer, 2016). On-the-job training, including internships, has proven to have the most promise for those encountering the greatest barriers (*ibid.*)

We heard an interesting presentation by Yuki Tol of Gemeente Amsterdam, which is looking at job creation specifically for people with disabilities. As part of this effort, city departments are incentivised through extra budget to cover wages. This sparked a lively discussion about the Dutch Participation Law, inclusion, belonging and more.

We also heard about examples from developing countries, such as Indonesia (Dadun and Peters, *et al.*, 2016). The two-track approach to development, where disability-focused work (stigma reduction as well as providing needed medical care) is coupled with economic development-focused programmes, such as microfinance loans, has proven more effective. Developed countries may also be able to learn from these successful, lower-cost approaches.

Given changes to work environments and practices, training providers and services supporting people with disabilities need to be aware of freelance/flexwork and the possibilities and pitfalls therein for disabled people (*see p. 20*).

For policymakers and programmes, flexibility, creativity, and individualisation are the keys to success. We found many research gaps in this area. When we are not sure what is effective, the smartest way to find out is through participatory research with disabled people.

## Stigma, disclosure and reasonable accommodations

Stigma is “an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one” (Goffman 1963: p. 3). Disability-related stigma can cause more difficulties for disabled people than their actual impairments: for example, Coleman *et al.* (2013) found that 60 percent of employers would not want to hire persons with disabilities and 20 percent of people would object to having a person with a disability as their manager—and 80 percent of discrimination against people with disabilities is based on ignorance and negative perceptions. These are especially strong when it comes to the two groups least likely to be in employment, people with intellectual disabilities and people with mental health conditions or neurological disorders, who are perceived as being unproductive and potentially dangerous.

### Aims

When trainees or employees are stigmatised, there is a direct impact on the individual. Perceived stigma affects self-esteem and motivation. Enacted stigma may include treating people with disabilities less favourably, or lead to discrimination or abuse. In addition, fear or reality of stigma by association can result in segregated and poorly funded/staffed training programmes or workplaces, segregation or shunning of disabled people, and prevent people with disabilities from feeling as if they belong in their training centre or workplace.

### Barriers

- To gain access to accommodations in training and work, people must disclose that they have a disability, and convince others that accommodations are reasonable and necessary. When disability is stigmatised, disclosure is risky, and responses may be negative.
- Some specialist training centres and workplaces use “branding” that marks trainees/employees as part of stigmatised groups.

### Facilitating factors

- Legislation against forms of enacted stigma, e.g. discrimination and abuse
- Avoiding and undoing segregation in training and work
- Visibility of non-stigmatised disability identities

### Recommendations

- Support individuals to improve their self-esteem and resilience in the face of stigma.
- Education, including anti-stigma campaigns (for example, Samen Sterk Zonder Stigma in the Netherlands) and targeting public attitudes formed via the media or other sources.
- Replacing stigmatising cultural stereotypes with more realistic views: music and video are good tools here.
- Consider ways of facilitating disability disclosure and accommodation that are not stigmatising.

## Supporting freelancers and flexworkers with disabilities

One of the realities of the modern, Western employment market is that a growing percentage of workers are self-employed. Whether this means running a small business, being a self-employed freelancer, being a “flexworker” on a short-term or changeable contract, or striving to earn money via the precarious “gig economy,” this kind of work can be characterised as having both benefits and risks for people with disabilities. As early as 2003, researchers had found that disabled people were twice as likely as non-disabled people to work in part-time contingent jobs. While the flexibility was seen as positive by some, such work also paid little, and in reality workers had very little power to change their schedules or practices (Schur, 2003).

This is something that disabled workers in the developing world already know, as for them, self-employment and precarious labour are already a way of life for the majority.

For disabled employees, not being completely reliant on one employer can be a plus—there is a lower barrier to disengagement, and sometimes higher potential for self-management of working hours and conditions. On the other hand, freelancers/flexworkers do not usually have access to employee benefits, and there is a power differential between employer and freelancer/flexworker for all but the most high-value contract employees or entrepreneurs.

### Aims

- To ensure that disabled workers and new entrants to the labour market are not disadvantaged as compared with non-disabled workers.
- To maximise the benefits of freelancing/flexwork for disabled workers who may need a variable work schedule or tempo.

### Barriers

- Poor communication between freelancers/flexworkers and employers
- Imposition of precarious terms of employment
- Unacknowledged intersectionality between disability status, gender/caring duties, and temporary/freelance status at work
- Constant renegotiation of terms, including disability-related adjustments
- “Outsider” status—not belonging; no influence on policies and practices of clients for self-employed persons or of temporary employers

### Facilitating factors

- Deliberately including freelancers/flexworkers in meetings and other decision-making forums
- Ensuring that freelancers/flexworkers have access to workplace adaptations and support
- Ensuring that freelancers/flexworkers have access to continuing professional education

## **Recommendations**

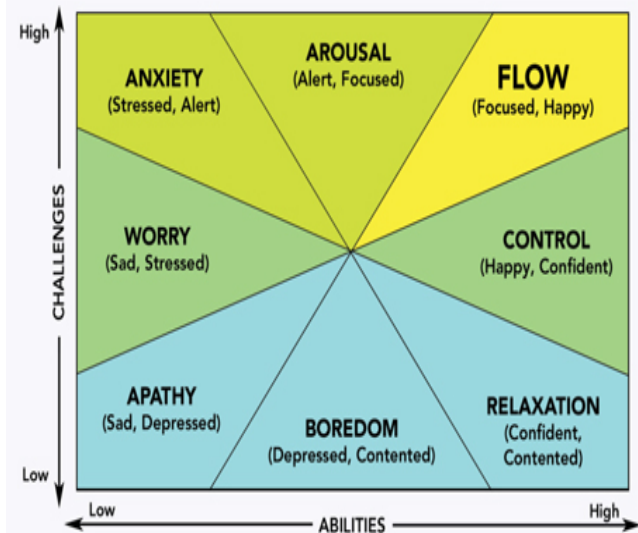
We recommend that companies contracting with freelancers and individual entrepreneurs or utilising flexworkers extend the same consideration to those with disability status as they do to their own workers with disabilities. This may require new forms of disability awareness work, and thinking of new ways to ensure that freelancers/flexworkers receive the adaptations and support they need. In the past, the Access to Work scheme in the UK has provided positive examples of ways to support self-employment (although austerity budgets and policy changes have undone much of this good practice). State programmes that support job-seekers need to be creative—for example, providing job coaches to disabled people who are freelancing or starting small businesses as well as to those who are directly employed; considering ways to allow people to mix being in receipt of essential benefits and support services with short-term or freelance work without penalties or excess bureaucracy. We believe that programmes developed to help get women and minorities into business will often offer good practices that can be adapted.

Training programmes are needed that prepare disabled people with the skills they need for success as freelancers/flexworkers, such as contract negotiation and negotiating disability accommodations.

We found a number of interesting examples of programmes supporting disabled people to become entrepreneurs, in both the developing and developed world. These included specialist “business incubator” programmes.

## Stress in training and work

Stress can be defined as a state of mental or emotional strain or tension resulting from adverse or demanding circumstances. Uncontrolled, negative stress (distress) can be a disabling factor, with impacts including “burnout,” absenteeism in training or work,



Mihály Csíkszentmihályi's model of flow as related to challenge and ability.

productivity, and inclusion (Mutkins *et al.*, 2011). However, managed, positive stress is can be a positive factor in training and work. We looked at Mihaly Cziksentmihalyi's model of flow (1996, *see left*), which puts periodic stress into perspective. As this model indicates, dangerous stress occurs when low ability intersects with high challenges—a situation that fits the experiences of many people with disabilities in training and work (Okoro *et al.*, 2007), with predictable results, including low training programme completion rates, high rates of training/work absence, and high “burnout” risk for employees with disabilities.

Another relevant model is the Job Demands-Resources model. Job demands refer to

“those physical, psychological, social, or organizational aspects of the job that require sustained physical and/or psychological (cognitive and emotional) effort or skills and are therefore associated with certain physiological and/or psychological costs,” while job resources refer to “those physical, psychological, social or organizational aspects of the job that are either/or (a) functional in achieving work goals (b) reduce job demands and the associated physical and psychological costs, (c) stimulate personal growth, learning and development.” (Bakker & Demerouti, 2007: p. 312). Job resources are important in their own right, but may also buffer the impact of job demands. Job demands in the absence of job resources is assumed to lead to negative outcomes as a result of a depletion of energy (health impairment process. The JD-R model provides insight into the relationship between job characteristics and various work outcomes, including burn-out, engagement, commitment, absenteeism and job, and reminds us to be attentive to ensuring job resources are in place to help balance out potential stress.

### Aims

- To minimise uncontrolled stress and its antecedents.
- To ensure that trainees and workers remain safe and healthy.
- To prevent “burnout,” absenteeism and low productivity.

### Barriers

- Fluctuating or high work demands are common in many modern workplaces.

- Lack of autonomy is common in many modern workplaces, especially but not only in low-paid work.

### **Facilitating factors**

- Realistic understanding of individual capabilities.
- Organised workload with autonomy reduces distress (van Ruysseveldt and van Dijke, 2011).
- Scaffolding learning tasks/work tasks to ensure people have the information, tools and support needed to work through occasional periods of stress.

### **Recommendations**

As Czicksentmihalyi's model indicates, there are two ways to avoid debilitating stress: keeping workload low or increasing the learner's/worker's level of ability; stress can be managed through ensuring sufficient job resources (such as social contacts, meaningfulness, autonomy, and skill discretion) are in place to create balance. Attention to both sides of the equation will both keep stress in balance with achievement and boost productivity.



## Mentoring and supportive feedback

We found two definitions of mentoring, both of which may be appropriate for some people with disabilities in some circumstances. First, mentoring can be defined as a time-limited, goal-orientated relationship that supports both personal and vocational learning and development. Essentially, an experienced person provides, within a trusting atmosphere, non-judgemental guidance and support to a less experienced person through a variety of methods including role modelling, guidance and problem solving (Western, 2012).

Brown *et al.* (2010) conceived of mentoring somewhat differently, defining it as a dynamic, reciprocal, long-term, formal or informal relationship that focuses on personal and /or professional development. In this model, a mentor is a sounding board and guide who provides perspectives and resources, and asks thought-provoking questions. In Brown's ideal mentoring relationship, mentors and mentees learn and teach each other. Mentoring was found to be demonstrably successful for students in higher education (Lunsford *et al.*, 2012), where it impacted students' sense of belonging, capacity for socially responsible leadership, deep and strategic learning approaches, and self-confidence in professional skills and abilities.

### Aims

- To provide the right support and advice at the right time, in the right way
- To inspire and encourage trainees and employees with disabilities.

### Barriers

- In many programmes and workplaces, the lines between mentoring, coaching and training are blurred and confusing.
- Currently there are several programmes worldwide focused on e-mentoring, despite the fact that we identified research gaps regarding the efficacy of mentoring, skills needed to be a good mentor, and other aspects, before adding a new delivery form to the process as well.

### Facilitating factors

Deci and Ryan's Self-Determination Theory (2000) was suggested as an available framework to support effective, motivational mentoring (Akkerman, Kef and Meininger, 2017).

### Recommendations

Mentoring has great promise, but is also an area where there is great research need, especially for people with intellectual and developmental disabilities and those who are non-verbal. As Brett (2016) found, this is a group that needs extra attention.

There is reason to believe that people who themselves have disabilities can be especially good mentors for trainees and workers with disabilities (Schwartz and Kramer, 2017).

## Belonging—Integration of people with disabilities into school or work groups

Training centres where people prepare for working and the workplace remain key places where long-term relationships are formed. They are places where individuals want to feel like they are part of a community, no matter what kind of work is carried out. Training and work are therefore spaces and activities in which belonging—a subjective feeling of being in the right place, of being valued as a contributor—is sought. It isn't that people need to feel like they are 'just like everyone else' in their training centre or workplace, but instead they want to feel that they are accepted as they are, and that they make a valued contribution to a common goal.

### Aims

- For disabled trainees/employees to feel that they fit in.
- For co-trainees and co-workers to feel that disabled trainees/employees fit in.
- To ensure that disabled trainees/workers build social capital during training/work.

### Barriers

- Low expectations
- Low self-esteem
- Stigma
- Lack of opportunity
- Segregation and self-segregation
- Hiring and pay of disabled workers on different terms than non-disabled workers

### Facilitating factors

- Access needs are understood and accommodated to facilitate participation and achievement (Ward and Baker, 2005; Zolna, Sanford, Sabata and Goldthwaite, 2007).
- Attention is paid to building realistic self-esteem based on increasing achievement and autonomy—create possibilities for experiencing success.
- Availability of life-long learning and training, including coaching and training on the workfloor.
- Inclusion from an early age so that diversity is the norm for all.
- Training and coaching for networks surrounding disabled people and educating wider society about diversity and inclusion.

### Recommendations

Working to discourage segregated training and workplaces will maximise belonging and fight stigma and low self-esteem. It is important to deliberately provide opportunities for personal growth and skill mastery (Schippers, 2010) and ways to demonstrate this to others. Companies need to see that by increasing workplace diversity, they can benefit in multiple ways—only then will they be incentivised to include disabled employees in planning,

discussions, decision-making. Finding and highlighting positive examples is crucial, and can be done in creative and empowering ways (Lunch and Lunch, 2006).

The research gaps here are large, and we recommend targeted participatory action research in training programmes and workplaces as a way to both create and evaluate the impact of change.

## CONCLUSION—AND A CALL FOR ACTION

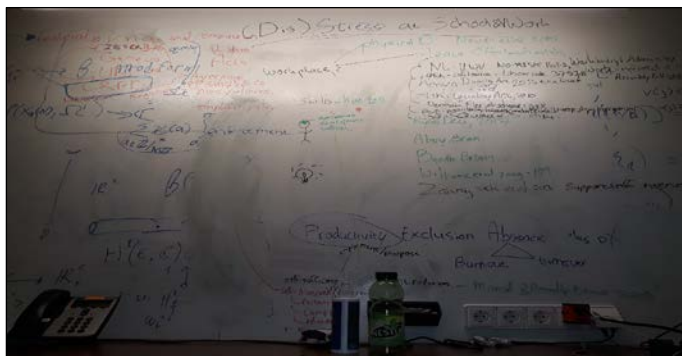
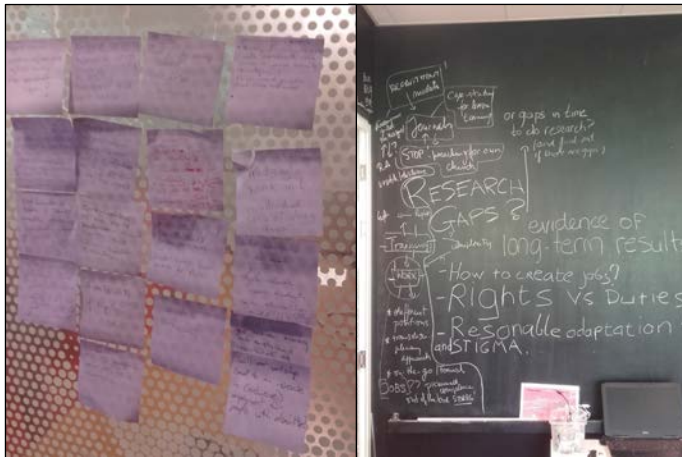


At some point during an evening dinner cruise around the lakes near Leiden that our Lorentz Centre hosts had thoughtfully organised for us, talk turned to pirates, and it became something of a running joke. The comparison wasn't to do with stealing other people's gold—it came from a humorous observation that pirates might have been the most successful fully inclusive society ever—think of pirates, and you immediately think of eye-patches, peg-legs, the wily and formidable Captain Hook, and a wildly diverse cast of brave, swashbuckling characters, each bringing specific skills to the raiding party, and all sharing equally in the booty.

A great metaphor for the society we'd like to see (again, minus the stealing).

We would now like to encourage all readers of this report to join our rebel band of pirates, to set sail from our comfortable ports, office chairs and ivory towers and into uncharted territory. How?

- **Speak up** when you know that existing services, programmes, and policies are not achieving good results for people with disabilities.
- **Make connections** between lack of full inclusion of disabled people when policies and plans are made regarding education and work, and poor results—and do something about it, at individual, programme and societal levels
- Start by **including a range of disabled people** at the very top of your own organisation's planning and policymaking procedures. Do not accept exclusion, tokenism, or rubber-stamp processes.



# WORKING TOGETHER

Our own work methods were more prosaic than piratical, but in metaphorical terms, the Jolly Roger flew: we challenged each others' assumptions, formed ad hoc teams to work on tricky problems, wrote on every available surface, and had quite a few late-night discussions over glasses of grog. The photos on these pages provide a glimpse of some of the many ways we worked collaboratively during the Lorentz Centre workshop.

Some of us were already personally acquainted through our workplaces or other projects, but most knew each other only through our collaborative work online before the workshop. Arriving together in Leiden was a bit like being thrown together on a ship, not sure of who would emerge as a temporary leader, who would provide cool-headed counsel, and who would gleefully set sail off in an unexpected direction.

We also practiced what we preached: our group of researchers was international and fully inclusive of people with disabilities.





From our first day in the same physical space, a call was issued to set aside self-imposed constraints derived from past experiences when rules, regulations, funding or programme limitations meant that things had to be done a certain way. Instead, we made a “pirate’s agreement”: to allow ourselves to be idealistic, but also to challenge the research basis for values and beliefs; to respect what each co-researcher brought to the table, regardless of formal qualifications; to put successful inclusion of people with disabilities in training and work as our first priority.

### **Addressing research gaps.**

We were dismayed at the large and unexamined knowledge and evidence gaps that we uncovered during our collaborative research. We found copious information from people with disabilities, from blogs, DPOs and occasional mentions in the margins of official reports, that had simply not filtered into the jargon-filled policy and practice documents that those of us charged with supporting disabled people into education and work are expected to navigate by. From the lack of research into effective ways to put a stop to the pervasive bullying of disabled people to roadblocks to redesigning places and procedures using UD/UDL, we saw ample evidence that the opinions, desires and needs of people with disabilities are routinely ignored, and that most programmes are still developed and run in ways that mainly suit non-disabled managers.

### ***We can do better.***

The main solution to this problem lies within the people such programmes are meant to serve. By putting collaborative research and participatory policymaking at the centre of our organisations—not as an occasional add-on or a side project, but as the main way we develop and act on evidence—organisations and programmes can move forward quicker, be more responsive, and truly meet the demand for inclusive solutions that get results.

For the group that came together at the Lorentz Centre in 2017, the next step is distribution of this report, and expanding it into a book. Many of us will also be launching new research projects or making changes where we work.

For researchers, practitioners and activists of all stripes who read this report, we ask that you consider ways in which you can incorporate these findings to transform how people with disabilities are supported into relevant education and meaningful work.

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**DISABILITY STUDIES**

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Stadsring 2 / Meet & Discover, 3811 HR Amersfoort, Netherlands  
+31 (0)619933345 [info@disabilitystudies.nl](mailto:info@disabilitystudies.nl)